



**PINNT**

A SUPPORT GROUP FOR PEOPLE  
RECEIVING ARTIFICIAL NUTRITION

# Parenteral Feeding: Your Questions Answered.

Paediatrics

Questions frequently asked by parents/carers of children  
requiring Parenteral Nutritional Therapy with Answers supplied  
by fellow patients.

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2014

What is Parenteral Nutrition?

Parenteral Nutrition (PN) is a means of supplying your body with nutrients and water which bypasses the digestive system. This is achieved through the insertion of a catheter directly into the bloodstream, through which a feed that is specific to your needs is administered. This is commonly referred to as Total Parenteral Nutrition (TPN).

What do the letters TPN mean?

TPN is a common abbreviation for TOTAL PARENTERAL NUTRITION. This literally means to eat (-enteral) through the vein (par-). However the terms PN (Parenteral Nutrition), HPN (Home Parenteral Nutrition) and TPN are often used interchangeably.

How will the nutrition enter my child's body?

A very fine soft tube known as a catheter is inserted by a doctor under the skin of the chest wall and into a large vein that leads to the heart. A local anesthetic will be administered to minimise the discomfort of the procedure and depending on the age of the child a sedative may also be given while the catheter is being inserted. In some cases it may be necessary for the child to be put to sleep whilst the catheter inserted. Once the doctor has confirmed that the catheter is in the correct position it can be connected to a container of PN fluid using a giving set.

Why does my child need PN?

There are a number of reasons why your child needs parenteral nutrition, but basically it is due to all or part of their digestive system not working correctly. This can be due to a Gastro-intestinal disorder that severely limits the ability to absorb nutrition in the normal way, or that the child is unable to swallow, or move the food through the digestive system in the normal way

PN can also be used to supplement your child's diet, thus making up for the nutrients they are not getting through their eating. This may be due to a condition such as Short Bowel Syndrome, where some or most of the small intestine has had to be removed. It is in the small intestine that the nutrients are absorbed into the blood stream and with the removal of parts of the small intestine insufficient nutrition can be absorbed from eating.

How long will my child need to be on PN?

Some patients will require PN for only a short time, such as to permit the digestive system to rest following surgery or illness. For others they will require PN for the rest of their lives. With advances in medical and surgical interventions it may be possible to come off PN in the future, but this will be regularly reviewed by your child's medical team, with whom you will be involved in such discussions.

Why is nutrition so important for my child?

Complete or total nutrition is especially important for the growth and development of infants, children and teenagers. If insufficient nutrition is experienced during these stages of development then he or she may have developmental and/or growth delay, he or she may therefore not reach the height or weigh the same as other children their age. Infants especially may not reach the developmental milestones at the same age as you would expect, which may hinder further growth and development in later life.

How will my child get all the nutrition it needs from PN?

Your child's doctor and the nutrition team will calculate the amount of nutrients your child requires in their PN to keep their body well nourished and able to support normal growth and development. Regular review of your child's progress will be done, which will factor in not only the current medical situation which resulted in the need for PN, but also the growth and development stages they are at. Accurate height and weight measurements will be taken along with blood tests and hydration status indicators to ensure the body is getting all the nutrients required and adjustments can be made to ensure that your child continues to achieve optimum nutrition as they grow.

Will my child have to stay in hospital?

No, for the majority of children who require PN on a long term basis, they are allowed to go home where their parents can administer the nutrition. This will not be done until you, the parent have been fully trained up on the protocol regarding the care for the central line, the administration of the feed and the hygiene requirements. All aspects of the care package will be explained and the team will decide when they feel that everything is in place to support both yourself and your child. Arrangements will also be made to ensure that everything you require is delivered directly to your home, including the feed and the equipment needed. You will have regular visits from your homecare team and a list of contact details and protocols to follow in case of complications or questions.

You will not be expected to take anything on until you are comfortable and confident that you can manage them. Support will be available to you from your medical team at all times.

When will my child be fed?

Most people on PN feed whilst they are asleep. This may disturb your child's sleep pattern to begin with but it does allow freedom during the day. Your hospital or nutrition unit will decide on the number of hours they have to feed and this will vary depending upon their individual requirements.

Will they be confined to bed?

HPN should not be restricted to lying in bed or staying at home it is necessary for your child's individual needs. Portable feeding pumps have made it easier to be mobile whilst receiving parenteral feed. Not all patients want to use a portable pump but improved mobility can be achieved with smaller drip stands for use around the home.

Will my child need to brush my teeth?

Whether your child can eat and drink something or nothing at all, it remains very important that you maintain good oral and dental hygiene. Continuing to brush their teeth at regular intervals and to routinely use mouthwashes are important as plaque can quickly build up, especially if they experience a dry mouth.

How will PN affect my child on a day to day basis?

This will depend on the symptoms of their underlying illness, but you may find that as they get older and more used to the feeding situation then they adapt accordingly. Children are surprisingly adaptive, especially when they have grown up with something and may not think themselves any different from anyone else as they do not know any other. For older children it may be more difficult and they may feel restricted by their nutritional regime, but support will be given to them when it is needed.

How will having a child on PN affect my life on a day to day basis?

At first, especially with small children or infants it may seem overwhelming and totally disruptive to your daily life, but utilising the support of the medical team and those around you will help you to go about things in a fairly normal and routine way. You do not need to try and manage everything on your own, there are support systems to help and your medical team will advise you on them as and when you require them.

As your child gets older, you may find that they are willing and confident enough to start and manage their PN themselves. They may practically take over the setting up and the running of the feed, which although may be difficult for you to let happen at first is something that they will need to be able to do and with your support they will achieve.

How will people react to my child?

When disconnected from the feed it will not be obvious to anyone that they require artificial nutrition as the catheter will be concealed underneath your clothing.

How will it affect my family and friends?

The feeding is organised to cause as little disruption as possible to the lives of your child, yourself and your family. By the time you leave hospital, your family and friends will have had some time to adapt to the new lifestyle. Once at home you can decide how much or how little you want to tell people about your child's therapy (*continued ...*)

How will it affect my family and friends?  
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It is advisable that at least one relative or friends should be familiar with the practicalities of home PN. It is far more beneficial to receive encouragement and support rather than sympathy.

Will I be able to cope with their needs?

Your ability to cope will have been carefully assessed by your child's nutrition team prior to your child leaving hospital, and you will only have been allowed to take them home because the doctors and nurses have confidence in your ability to look after you child & yourself.

If you have been trained at home you will still have access to all the usual support networks and should let people know if you do not feel you are coping or if things change.

It is important that any fears you may have are relayed to your child's nutrition team who will provide support whenever you need it. If you have nurses coming to your home then you can chat to them if anything worries or concerns you.

Nearly all parents feel anxious and frightened when their child is discharged home and the hospital staff are used to parents contacting them after discharge. You may receive the support of a homecare nurse who can be especially supportive to parents of new patients. Your ability to cope may also change depending on how your child's underlying condition affects you on a day to day basis. It is not unusual for people to have mixed emotions even after a long time on HPN.

Is it safe for my child to have a pet?

Lots of patients on PN have pets and they are perfectly safe to do so. There are obvious precautions if you do own pets and have a central line, etc. but they are really about being sensible and protecting your line and always washing your hands after you are in contact with them.

If you have a guinea pig, hamster, or other little animal that like to nibble on anything and everything, then it is advisable to ensure that they never get close to the central line or giving sets.

Can I take my child on holiday?

Everyone needs a holiday and you and your child are no different. The treatment need not prevent your child from travelling. Obviously whether you are travelling in the UK or abroad there will need to be special arrangement made to ensure that everything goes safely. Your medical team and your homecare company will help you to make all of the necessary  
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Can I take my child on holiday?  
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arrangements regarding feeding equipment and supplies, information on travel and flight arrangements & requirements and advice on what to do in an emergency.

Can I let my child play sports?

If your child is feeling well enough then there are many sporting activities they can enjoy. Common sense should prevail at all times. It is of greatest importance that discomfort or harm occurring to their catheter is avoided. You should talk to their nutrition team before allowing them to take part in water sports or any activity which is very strenuous.

Can I let my child get their dressing wet?

Central line dressing should be kept dry at all times although each individual unit or hospital will have their own guidelines for water activities, e.g. bathing, showering and swimming. If you are unsure what you can let your child do, ask for advice.

Will they experience a lot of complications being fed by PN?

With careful management and following the hygienic protocols described by your hospital nutrition team, you should find that there are very few problems, but it is unrealistic to pretend that nothing can go wrong and therefore you will be given information about the types of things that can occur and more importantly the initial signs and symptoms to be aware that something may not be right.

What are the common complications that can arise when on PN?

The most common complication to arise from PN is INFECTION and recognising the early signs are extremely important. You will be given comprehensive information to recognise the signs and instructions on what you will need to do if you suspect your child has an infection. If this does not happen ensure you ask prior to discharge. Always make sure you know how to contact your medics outside of normal working hours.

Never ignore obvious signs of infection or complications.

All hospitals when discharging patients home on PN should provide written information on procedures, complications, contact details along with any other information they feel appropriate.

It is important to know that **not** all line infections result in the removal of the line, they should be preserved for as long as is possible in situ. A decision will be made depending on the type of infection as to whether a treatment plan can be instigated and successfully save the line. This will

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Common complications that can arise when on PN?

How will I know that my child's line is infected?

What would happen if the line is damaged or pulled it out by accident?

Some medical staff don't seem aware of how important the aseptic procedure is, should I tell them?

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vary but removing the line should not be seen as the only option. If you find yourself in a hospital other than your child's treating hospital it may be advisable for the consultant caring for your child makes contact with their usual consultant so they can discuss treatment options.

If your child have a temperature soon after they have started to feed then advice should be sought immediately or follow the instructions you have been given. You may also find they experience shaking, 'rigours'. Not all infection start soon after feed has been set up. If you find they have cold or flu like symptoms and just don't feel right contact your child's unit or follow the instructions you have been given. If you suspect that the line is infected seek medical advice immediately. The sooner the infection is diagnosed, or ruled out, the better it is for your child and their line.

The only way of knowing for sure whether the line is infected or not, is by having a blood cultures taken which will be monitored by your child's unit to see what grows. Watching for early indications of an infection are key to your child's personal well being - these include redness, pain and /or discharge from the entry site, and you may experience systemic symptoms such as fever, headaches, lethargy. If in doubt, ask, better to be safe than sorry.

Seek medical attention at once. Depending on type of damage to the line you will be given appropriate advice from your child's unit. Always clamp off the line if there is damage to the external segment of the catheter. It may advisable to ensure you have a pair of plastic clamps at home in the event that the clamp breaks, these can be requested from your child's unit or home care provider.

YES, always tell them! If anyone tries to attempt anything with your child's line that you are not fully happy with always say something. If you are not at your child's usual hospital then ask them to speak to your child's team for advice. There are variations in protocols but at no time should you feel your child's safety is being compromised. If you feel good practice is not being carried out ask to speak to the ward sister or the consultant currently looking after your child and get your point across. This is where written literature from your child's own unit or hospital is important to demonstrate the standards of care you use. Unfortunately there are still medical staff out there that are unaware of how important the lines are and remember not all staff are trained in Parenteral Nutrition and you will probably find that your

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Some medical staff don't seem aware of how important the aseptic procedure is, should I tell them?

What if we are on holiday and my child shows signs of complications?

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own knowledge is far more extensive than theirs. Try to work with people to ensure your child is safe and comfortable in their care; being in a hostile situation is non productive for all concerned.

Never be afraid to speak up, your child is not able to do it themselves and this is their life line, you have a voice, use it!!

What to do in the event of a complication while on holiday should be something considered well before departure or when it happens. Whether holidaying abroad or at home, you should have a plan. Consider who you would contact based on where you are going or how you would get back home. If travelling abroad it is essential that you have appropriate travel insurance to cover any medical care and medication your child may require. Medication and hospital costs can be expensive in some countries. When travelling to Europe ensure you take your child's EHIC card. Always check prior to departure that the EHIC card is valid. If applying via the internet for a EHIC card do not pay for it – these are free.

It is essential that if your child feels unwell, appears to be behaving in an unusual way or you suspect anything is not right you SEEK MEDICAL ATTENTION IMMEDIATELY, if only to reassure yourself that everything is ok.

If you are travelling abroad with your child then do consider that there could be a language barrier where English is not widely spoken or understood. If this is the case then you should consider ensuring that any relevant medical information supplied by your child's hospital is translated so you are able to convey key message to people who may be caring for your child

If the question above do not cover what you were looking for them please email PINNT at: [info@pinnt.com](mailto:info@pinnt.com) with questions and we will seek answers and add them to the list.

While this list of Q&A's has been answered to the best of our ability this does not replace individual medical advice that is provided directly to you. You should never accept anything you read as suitable for you without clearing it with your own healthcare professionals.

Each PN patient is an individual, while there are commonalities there are also huge variations even with PN, underlying conditions and personal expectations.



## Glossary of Common Terms.

**This is not an exhaustive list! If you hear any term that you don't understand, please ask someone to explain it to you.**

<b>AMINO ACIDS</b>	The building blocks of proteins, sometimes referred to as Pre-digested or Hydrolysed proteins.
<b>CATHETER</b>	A fine hollow tube used to introduce fluid into a vein. They are referred to by the manufacturer's name, e.g. Broviac or Hickman.
<b>CATHETER HUB</b>	The part of the catheter which connects to the giving set or catheter cap.
<b>ELECTROLYTE</b>	Mineral which conducts chemical energy when dissolved in water, particularly important in maintaining water balance and cardiac output. e.g. Sodium, Potassium.
<b>EMULSIFICATION</b>	The mixing of two substances that are not normally mixable with the use of a substance that can mix with each of them.
<b>ENTRY SITE</b>	The place where your catheter is inserted into the vein.
<b>EXIT SITE</b>	The place where the catheter comes through the skin (and is covered by a dressing) NB. Some catheters are implanted and the exit site is under the skin.
<b>FISTULA</b>	An abnormal opening between 2 organs, or between 1 organ and the skin. Some are the result of deliberate surgical intervention.
<b>GIVING SET</b>	Specifically designed tubing to connect the feed container to your catheter.
<b>HAEMATOCRIT</b>	The volume of the blood that is composed of red blood cells. This level can be used to detect early signs of Anaemia (low levels) and dehydration (high levels)
<b>HYPERGLYCAEMIA</b>	A high blood sugar level which if left untreated can lead to complications with eye sight, infections and ulcers.
<b>HYPOGLYCAEMIA</b>	A low blood sugar level (sometimes called a hypo), which left untreated can develop into a diabetic coma and death.
<b>ILEUS</b>	Paralysis of at least part of the Gastrointestinal Tract
<b>INFUSION</b>	The process whereby fluid is delivered into a vein.

## Glossary of Common Terms.

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<b>INTRAVENOUS</b>	Going directly into the vein.
<b>PARENTERAL</b>	“to eat via the vein” (literal translation)
<b>REFEEDING SYNDROME</b>	A condition which can occur during feeding after illness, caused by shift in metabolic activity. Requires medical treatment.
<b>SALINE</b>	Salt solution.
<b>SHORT BOWEL SYNDROME</b>	Resulting from the removal of a portion of the small intestine, with characteristic symptoms including impaired digestion & absorption.
<b>SEPTICAEMIA</b>	A widespread infection carried in the bloodstream.
<b>TOLERANCE</b>	The degree to which symptoms arise from an infusion of formula
<b>PN/TPN</b>	Parenteral nutrition/Total Parenteral Nutrition – when all the nutrients needed are delivered directly into the bloodstream